Registry information has shown that 1 in 2 people will now survive cancer for at least 10 years.

Achievements made possible by cancer registration information:

- research showing that there are at least 10 different types of breast cancer, which means treatments can be made more specific for each type
- monitoring whether cancers are becoming more or less common – for example spotting the rapid increase in skin cancer cases has led to prevention campaigns to promote staying safe in the sun and avoiding sun beds
- improvement of the breast cancer screening programme, and the decision to introduce flexible sigmoidoscopy (a technique for examining the bowel) as a method of screening for bowel cancer
- research around when and where patients are diagnosed with cancer, which showed that almost a quarter are diagnosed in an emergency. This has reinforced the importance of finding ways to get more patients diagnosed early

The more information we have in the registry, the easier it is to improve diagnosis and treatment.

What if I don't want my details on the cancer registry?

The benefits of the data collected by the cancer registry have been considerable and we are grateful that nearly everyone with cancer is prepared to share their data with the cancer registry. However, you can ask us to remove all of your details from the cancer registry at any time. These requests won't affect your treatment or care. If you wish to make such a request, you should email **optout@ncr.nhs.uk** or write to

Director
National Cancer Registration Service
Public Health England
Wellington House
London SE1 8UG

If you have any questions about cancer registration, you can get more information by:

- asking your doctor
- visiting the Cancer Research UK website at **www.cruk.org/cancer-registration** or the cancer registration website at **www.ncr.nhs.uk/patientinfo** where you will find a longer booklet
- and for any questions on cancer, speak to one of Cancer Research UK's nurses on freephone **0808 800 4040** (9am–5pm, Monday to Friday)

Cancer registration is crucial for progress against cancer, and is supported by all the main UK cancer charities and cancer patient groups.

Against Breast Cancer
Bowel & Cancer Research
Bowel Cancer UK
Brain Tumour Research
Brain Tumour Research Campaign
Brainstrust
Breast Cancer Campaign
British Lung Foundation
Core – the Digestive Disorders Foundation
Cancer52
Cancer Research UK
GIST Support UK
It's in the Bag
James Whale Fund for Kidney Cancer
Jo's Cervical Cancer Trust
Skcin – The Karen Clifford Skin Cancer Charity
Leukaemia & Lymphoma Research
Lymphoma Association
Macmillan Cancer Support
Marie Curie Cancer Care
Melanoma Focus
My Name is NOT Cancer
Myeloma UK
Pancreatic Cancer Action
Rarer Cancers Foundation
Sarcoma UK
Shine Cancer Support
Skin Cancer Research Fund
Target Ovarian Cancer
Teenage Cancer Trust
The Pelican Cancer Foundation
The Pink Ribbon Foundation
WMUK

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Public Health England

Protecting and improving the nation's health

Cancer Registration – what it is, the benefits of being on the register, and your options

NHS

CANCER RESEARCH UK

We've made great strides in recent years in our understanding of what causes cancer and how best to diagnose and treat it. But we can only continue this progress if we have information about the people who are developing cancer. We collect this information through a process called cancer registration.

Here, we explain why information about you and your cancer is recorded, how this information is used, and how, if you wish, you can see your information or have it removed from the registry.

What is cancer registration?

If you or your child has been diagnosed with cancer, or a condition that can lead to cancer, the medical staff looking after your health will pass information about you on to the National Cancer Registration Service.

This will include your name, address, age, sex and date of birth, as well as information about the type of cancer or condition you have, and your treatment.

The Registration Service has the government's permission to collect this information. To get a complete picture we will also link this information to your other health information and to patient surveys about your care, and may share it with the nurses and doctors who are looking after you.

Cancer registration helps scientists investigate possible causes of cancer and improve treatment options.

Your details drive progress in cancer prevention and treatment

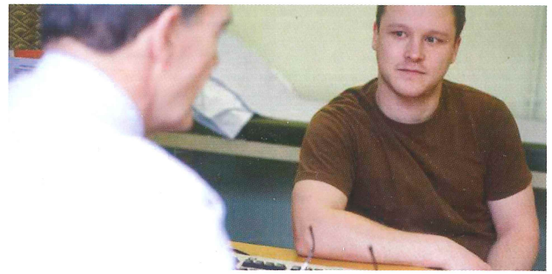
Cancer registration is the only way we can keep track of how many people are getting cancer and what types of cancer they have. Healthcare teams use this information to continually evaluate and improve services and treatment options for patients.

Cancer registration also fuels research into cancer, helping scientists investigate possible causes of cancer and improve treatments for the disease. This information is crucial for progress against cancer, and is supported by all the main UK cancer charities and cancer patient groups.

Is my information confidential?

Making sure your personal information is private and confidential is very important. Without your consent or a strict approval process, information that can be used to identify you will only be released to those providing your care, such as your hospital and doctor.

If you would like to see the information we have about you on the registry, we can give this to your doctor for them to share with you.



How will it benefit me?

There is no guarantee that having your information on the cancer registry will directly benefit you. However, we know that registry information is continually leading to improvements and new information on the prevention, diagnosis and treatment of cancer and so can help future generations.

In order to give each person the best possible care, we need to know how different cancers respond to different treatments – this information is held in the registry.

The registry could also make it easier for your doctor to see whether you could enrol in any clinical trials. If you have a family history of cancer, doctors can use the registry to find out what treatments worked best for your relatives and tailor your care accordingly.

Registry information is sometimes also used to find out which patients have had a particular treatment. This helps doctors identify any patients they need to contact about the treatment.